

Propuesta de gestión de datos en salud cardiovascular

EU Joint Action on Cardiovascular Disease and Diabetes (JACARDI)

Dr. Héctor Bueno

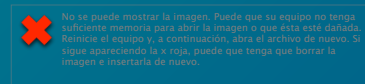
Grupo de Investigación Multidisciplinaria Traslacional Cardiovascular
Centro Nacional de Investigaciones Cardiovasculares (CNIC)



Profesor Asociado
Universidad Complutense de Madrid



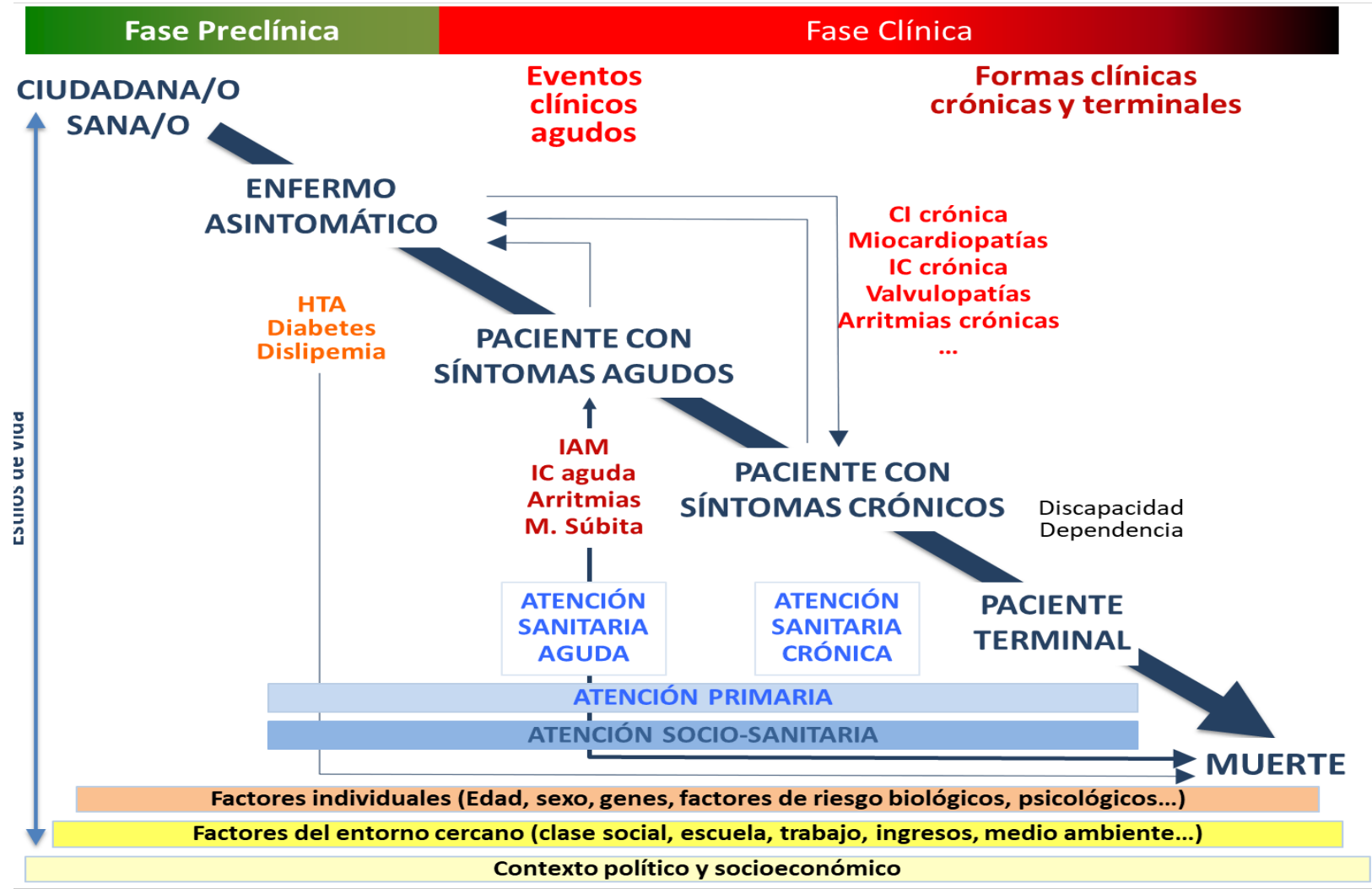
Servicio de Cardiología y Area de Investigación Cardiovascular. Instituto de investigación i+12
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Estrategia de Salud Cardiovascular (ESCAV)

Estrategia en Salud Cardiovascular del Sistema Nacional de Salud (ESCAV)



Estrategia de Salud Cardiovascular (ESCAV)

Estrategia en Salud Cardiovascular del Sistema Nacional de Salud (ESCAV)

Punto crítico TR-INFSCV: Disponer de información contrastada para conocer el estado de salud cardiovascular y de la atención a la ECV en la población

ACCIONES

- TR-INFSCV-ACC1.1. Desarrollar un mapa accesible para la consulta con los indicadores ideales de salud cardiovascular y de atención a la ECV
- TR-INFSCV-ACC1.2. Promover la realización de un plan de análisis sistemático y estructurado sobre el estado de la salud cardiovascular de la sociedad y de la atención a la ECV, identificando la información necesaria y sus fuentes, la manera más eficiente de obtenerla y la manera más homogénea de comunicarla



JACARDI

Joint Action on **CAR**diovascular diseases and **DI**abetes

Data availability, quality, accessibility and sharing: overview of the objectives of JACARDI

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JACARDI general information

- EU contribution: €53 Million
- Duration: 01 November 2023 – 31 October 2027
- Coordinator: Istituto Superiore di Sanità (Italy)
- Number of European Countries: 21
- Number of Partners: 76
- Pilots to be implemented: 142



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JACARDI scope and general objectives

- Support EU countries to **reduce the burden of CVD and DM** and related risk factors, both at individual and societal level, while assuring health systems sustainability and equity
- Enhance and promote the **implementation** of (cross-sectional) **best practices**, and **pilot testing** of innovative practices throughout the **whole ‘patient’ journey**

Project relevance

- Contribute to achieving the objectives of the **EU4H Programme**
- Strong **policy relevance** through the implementation of new evidence-based policies and actions
- Development of a **roadmap from the pilot implementation** which will operate as proof-of-concept case studies to potentially extend and scale up the experience at national/regional level and/or transfer the pilot to other EU countries

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Complementary with other actions

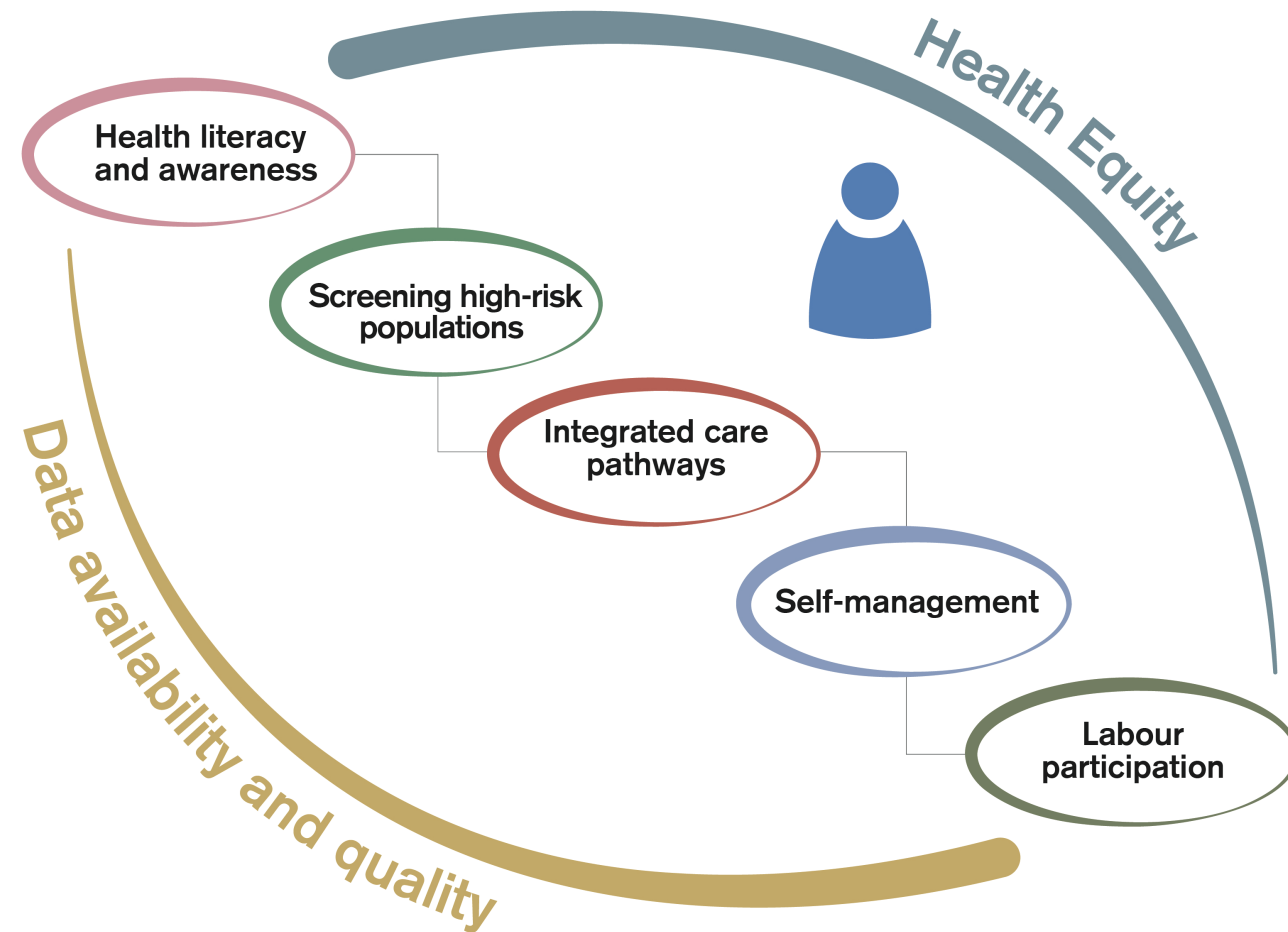
- Building on what already exists approach (do not reinvent the wheel)
- Follow the orientation of the Healthier Together EU Non-Communicable Diseases Initiative launched by the EC
- Built on the experiences of previous and ongoing JAs: CHRODIS, CHRODIS-PLUS and Joint Action Health Equity Europe (JAHEE), JAs JADECARE and CARE4DIABETES, BestReMap, EU STOP Project

- Align and collaborate with **JAPreventNCD** for synergies in high-level policy sustainability
- Synergies with **action grants on “prevention of NCDs – cardiovascular diseases, diabetes and other NCDs”** to integrate activities and maximise the impact between JACARDI and the funded projects.

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Patient journey

- Implementation of best practices, and pilot testing of innovative practices
- Addressing:
 - healthy people
 - people at risk of developing CVD/DM
 - people with diagnosed CVD/DM at risk of disease progress and multimorbidity
 - Both at individual and population level and within different settings



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JACARDI
Joint Action on **CAR**diovascular diseases and **DI**abetes

WP7 - Data availability, quality, accessibility and sharing

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- Task 7.1. Mapping of current data and data source availability** to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps
- Task 7.2. Design and develop plans to improve data availability and quality**
- Task 7.3. Standardisation and harmonisation** of data and data collection, integration and sharing
- Task 7.4. Description and evaluation of data value, collection and integration**
- Task 7.5. Implementation and assessment of pilot projects**
- Task 7.6. Pilot scaling up**

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Task 7.1. Mapping of current data and data source availability to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps



To map the availability of current data and data source to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps.



Sub-task 7.1.1. Defining a framework with all the needed information to know the status of cardiovascular health, CVD, and DM in all EU countries.

Sub-task 7.1.2. Mapping the availability of information and data sources to understand the reality of CVD and DM in each country

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Task 7.1. Mapping of current data and data source availability to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps

Data architecture Framework

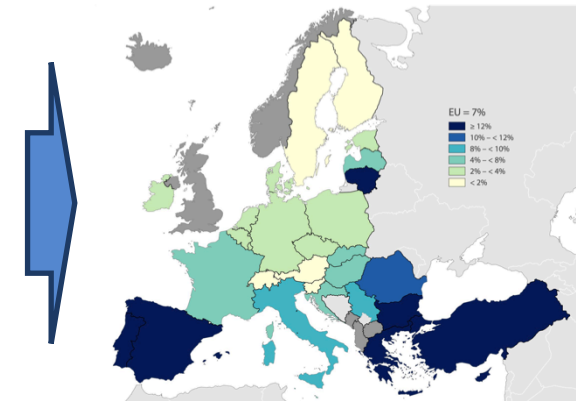
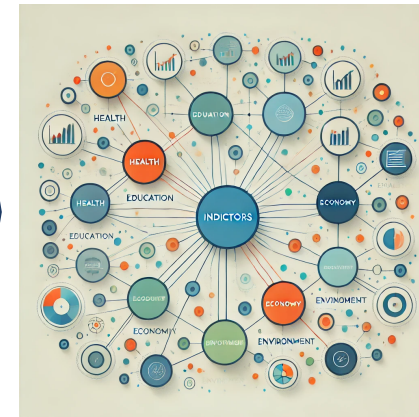
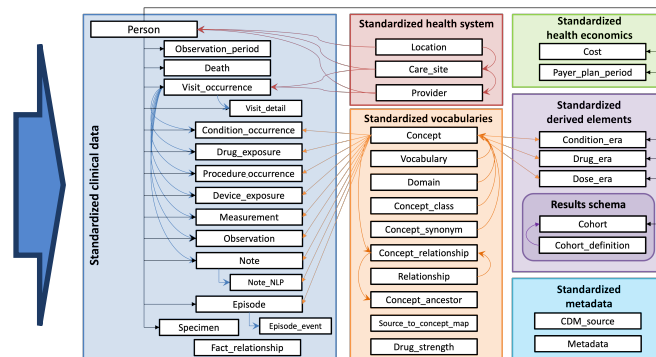
Standards OMOP CDM

Indicators

Mapping

3.1.1 Population level

Setting Dimension	Epidemiology			POPULATION LEVEL					Quality Indicators		
	inc	Prev	M	Diagnosis	Care Med Therapies	Procedures	Clinical	Cost/Value	Struc	Process	Results
1. CV RISK FACTORS											
1.1. Biological											
- Age (age strata)											
- Sex											
- Hypertension											
- Hypercholesterolemia											
- Diabetes mellitus											
- Body Weight (overweight, obesity)											
- Family history of CVD											
- Hormonal history (HRT, menopause...)											
- Medications											
1.2. Behavioural (lifestyle)											
- Smoking											
- Diet											
- Physical activity											
- Sedentarianism											
- Sleep patterns											
- Alcohol consumption											
- Illicit drug use											
2. CARDIOVASCULAR DISEASES											
2.1. Cardiac diseases											
2.1.1. Ischemic Heart Disease											



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Task 7.1.1. Defining the **framework** with the needed information to know the status of cardiovascular health, CVD, and DM in EU countries

Measures	Setting	Dimensions	Domains	Subdomains	Standards
Risk Factors - Behavioural - Biological	Population	Epidemiology	Incidence Prevalence Mortality		OMOP
Disease-related - CVD - DM	Healthcare system (Outpatient)	Clinical	Care Results	Diagnosis / Medical Therapy / Procedures Use / Effectiveness / Appropriateness / Economical / Safety / Morbidity / Mortality / Cost-Value / PREMS-PROMS...	OMOP
Modifiers of disease or care - Comorbidities - Non-medical	Healthcare system (Inpatient)	Quality	Structural Process Results	Specific QIs	OMOP? ?

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Setting	POPULATION LEVEL										
Dimension	Epidemiology			Care			Results		Quality Indicators		
	inc	Prev	M	Diagnosis	Med Therapies	Procedures	Clinical	Cost/Value	Struc	Process	Results
2. CARDIOVASCULAR DISEASES											
2.1. Ischemic Heart Disease											
- Acute coronary syndromes											
- AMI											
- Chronic IHD											
2.2. Heart Failure											
- Acute Heart Failure											
- Cardiogenic shock											
- Chronic Heart Failure											
2.3. Rhythm Disturbances											
- Sudden death / OOH CA						CPR			AED	Time	
- Atrial fibrillation					OAC						
- Other SV arrhythmias											
- Ventricular arrhythmias											
- Slow rythms											
2.3. Heart Valve diseases											
2.4. Pulmonary hypertension											
2.5. Peripheral arterial disease											
2.6. Congenital Heart disease											

Task 7.1.1. Defining the **framework** with the needed information to know the status of cardiovascular health, CVD, and DM in EU countries

Setting	POPULATION LEVEL										
Dimension	Epidemiology			Care			Results		Quality Indicators		
	inc	Prev	M	Diagnosis	Med Therapies	Procedures	Clinical	Cost/Value	Struc	Process	Results

Setting	OUTPATIENT CARE LEVEL (PRIMARY CARE / SPECIALISED CARE)																	
Dimension	Epi			Care			Results									Quality Indicators		
	in	Pr	M	Diagnosis	Med Ther	Procedures	Use	Effectiveness	Appropriateness	Safety	Morbidity	Mortality	Cost / Value	PREMS	PROMS	Structural	Process	Results

Setting	HOSPITAL CARE LEVEL																	
Dimension	Epid			Care			Results									Quality Indicators		
	In	Pr	M	Diagnosis	Med Ther	Procedures	Use	Effectiveness	Appropriateness	Safety	Morbidity	Mortality	Cost / Value	PREMS	PROMS	Structural	Process	Results

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Setting	OUTPATIENT CARE LEVEL (PRIMARY CARE / SPECIALISED CARE)																	
Dimension	Epi			Care			Results									Quality Indicators		
	in	Pr	M	Diagnosis	Med Ther	Procedures	Use	Effectiveness	Appropriateness	Safety	Morbidity	Mortality	Cost / Value	PREMS	PROMS	Structural	Process	Results
1. CV RISK FACTORS																		
1.1. Behavioral (life style)																		
- Smoking																		
- Diet																		
- Physical activity																		
- Sleep																		
- Alcohol																		
- ...																		
1.2. Biological																		
- Hypertension		P																
- Hypercholesterolemia		P																
- Diabetes mellitus		P																
- Weight		P																
2. CARDIOVASCULAR DISEASES																		
2.1. Ischemic Heart Disease		P																
- Acute coronary syndromes																		
- AMI																		
- Chronic IHD		P																
2.2. Heart Failure		P																
- Acute Heart Failure		I																
- Cardiogenic shock																		
- Chronic Heart Failure		P																
2.3. Rhythm Disturbances		P																
- Sudden death / OOH CA																		
- Atrial fibrillation		I	P	ECG	OAC						Stroke							
- Other SV arrhythmias		P																
- Ventricular arrhythmias																		
- Slow rhythms		P																
2.3. Heart Valve diseases		P																
2.4. Pulmonary hypertension																		
2.5. Peripheral arterial disease																		
2.6. Congenital Heart disease																		

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Setting Dimension	HOSPITAL CARE LEVEL																		
	Epid			Care			Results										Quality Indicators		
	In	Pr	M	Diagnosis	Med Ther	Procedures	Use	Effectiveness	Appropriateness	Safety	Morbidity	Mortality	Cost / Value	PREMS	PROMS	Structural	Process	Results	
2. CARDIOVASCULAR DISEASES																			
2.1. Ischemic Heart Disease																			
- Acute coronary syndromes	I				EBMT	PCI													
- AMI	I				EBMT	PPCI													
- Chronic IHD					EBMT	PCI, CABG													
2.2. Heart Failure																			
- Acute Heart Failure	I																		
- Cardiogenic shock	I																		
- Chronic Heart Failure					EBMT														
2.3. Rhythm Disturbances																			
- Sudden death / OOH CA				-	-	ICD													
- Atrial fibrillation					OAC	Ablat					Stroke								
- Other SV arrhythmias						Ablat													
- Ventricular arrhythmias						Ablat, ICD													
- Slow rythms						PM													
2.3. Heart Valve diseases																			
2.4. Pulmonary hypertension																			
2.5. Peripheral arterial disease																			
2.6. Congenital Heart disease						Surg													

Task 7.1.1. Defining the framework with the needed information to know the status of cardiovascular health, CVD, and DM in EU countries

3.1. Comorbidities / Risk Factors	3.2. Potential non-medical Individual Sources of variability/inequity
- Alcohol abuse	- Age
- Smoking	- Sex
- Drug abuse	- Gender
- Risk factors: Hypertension, dyslipidaemia	- Ethnicity
- Overweight/Obesity	- Citizenship/health care
- Nutritional (malnutrition)	- Country of birth (EU Yes/No)
- Comorbidity Indices (Charlson, Elixhauser)	- Country of Parents' birth (EU Yes/No)
- Cancer	- Migration status
- Cardiovascular disease	- Language
o Coronary artery disease	- Religion
o Heart failure	- Economic level
o Atrial fibrillation	- Education level
o Cerebrovascular disease	- Employment
o Peripheral arterial disease	- Social class
- Chronic pulmonary disease	- Minority membership
- Chronic kidney disease	- Loneliness
- Liver disease	- Social exclusion (homelessness, extreme poverty)
- Peptic ulcer	- Home conditions
- Connective tissue disease	
- AIDS	3.3. Systemic sources of inequality
- Diabetes duration	Environmental pollution
- Diabetes complications	Political system and form of government
- Frailty / Dependence	Inequalities in power distribution
- Dementia	- Interregional differences in health
- Mental disease	- Territorial inequalities in the health system (financing, service provision, etc.)
	- Economic differences between regions (productive sectors, available resources)
	- Laws favouring the reduction of inequalities (gender, social)

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ing authority

Task 7.1. Mapping of current data and data source availability to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps

OMOP Common Data Model 5.4

Variable Information

Variable name:

OMOP table:

Variable Type:

What kind of variable is?

Simple

Composite

reset

If it is a composite variable, which OMOP variables are used in its design? (includes all variables separated by commas)

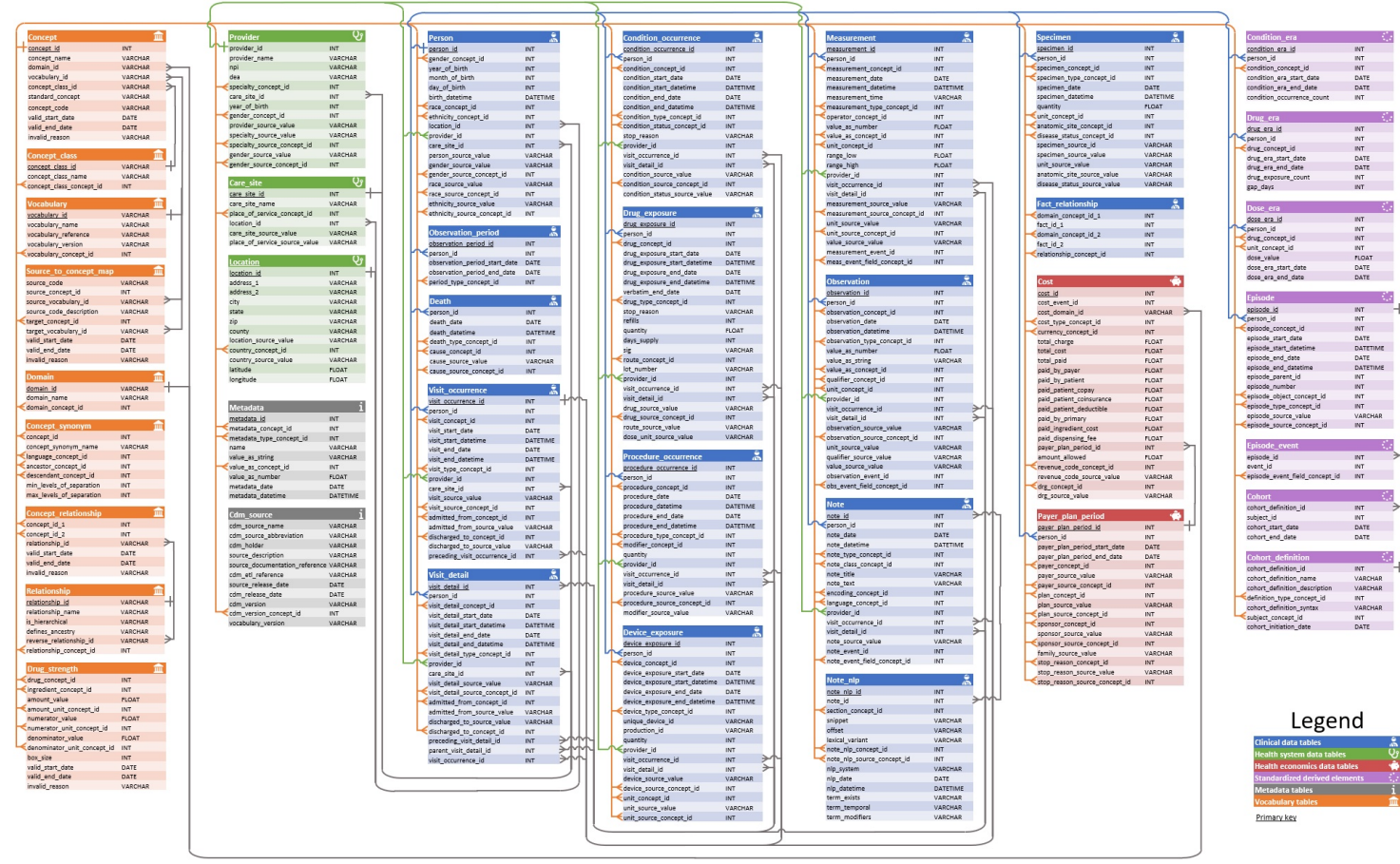
Expand

Is it a standard variable (included in official OMOP models)?

Yes

No

reset



Legend

- Clinical data tables
- Health system data tables
- Health economics data tables
- Administrative/Operational/Research
- Metadata tables
- Vocabulary tables
- Primary key


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Task 7.1. Mapping of current data and data source availability to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps

Indicator name	Measurement frequency/ frequency of measurement
Indicator title	Monitoring and evaluation framework
Indicator subtitle	Preferred data sources
Indicator code	Other possible sources
Category	Further information and related links
Subcategory	Purpose
Definition	Interpretation
Formula	Use
Numerator	Type
Denominator	Preference range
ID variable (CDM)	Reference period
Disaggregation/additional dimension	Limitations
Method of measurement	Responsible Institution

can be held responsible for them.

 Editing existing Record ID 1.

Record ID 1

Include the name of the indicator

Include the title of the indicator

Include the subtitle of the indicator

Include the proposal code of the indicator

Include the category of the indicator

Include the subcategory of the indicator

Describe how the indicator is defined, including the key parameters

Indicate the numerator of the formula of the indicator

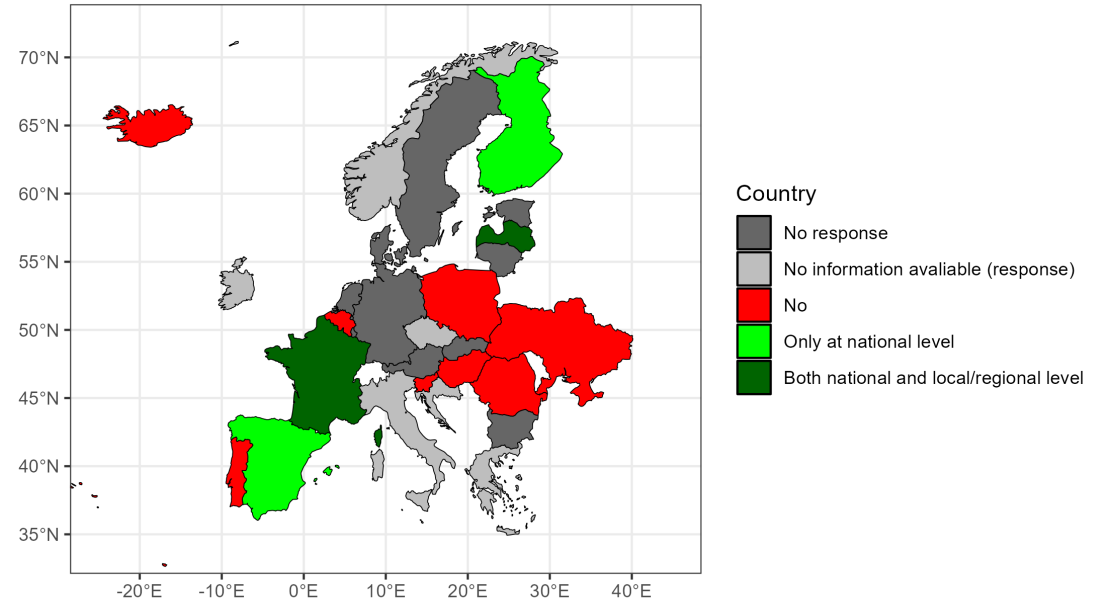
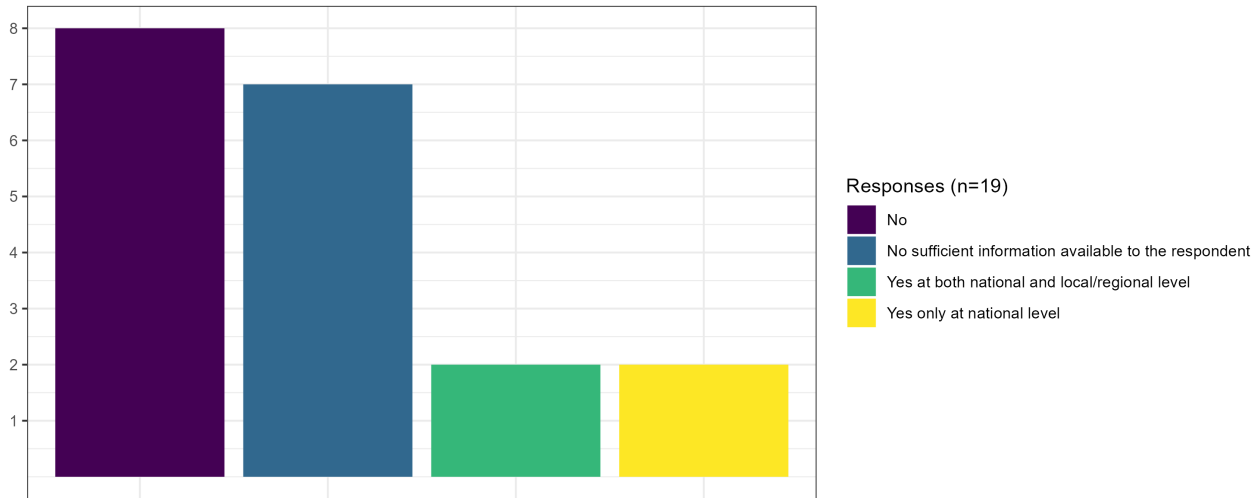
Task 7.1.2. Mapping the availability of information and data sources to understand the reality of CVD and DM in each country

- Mapping existing national and regional quality registries, activities, platforms or centres, networks, and their roles
- Mapping the coverage and extent of the available data (variables, measurements, assessments, methods of data collection, etc.)
- Identifying **country-specific gaps** and needs on CVD and DM data and information and harmonisation

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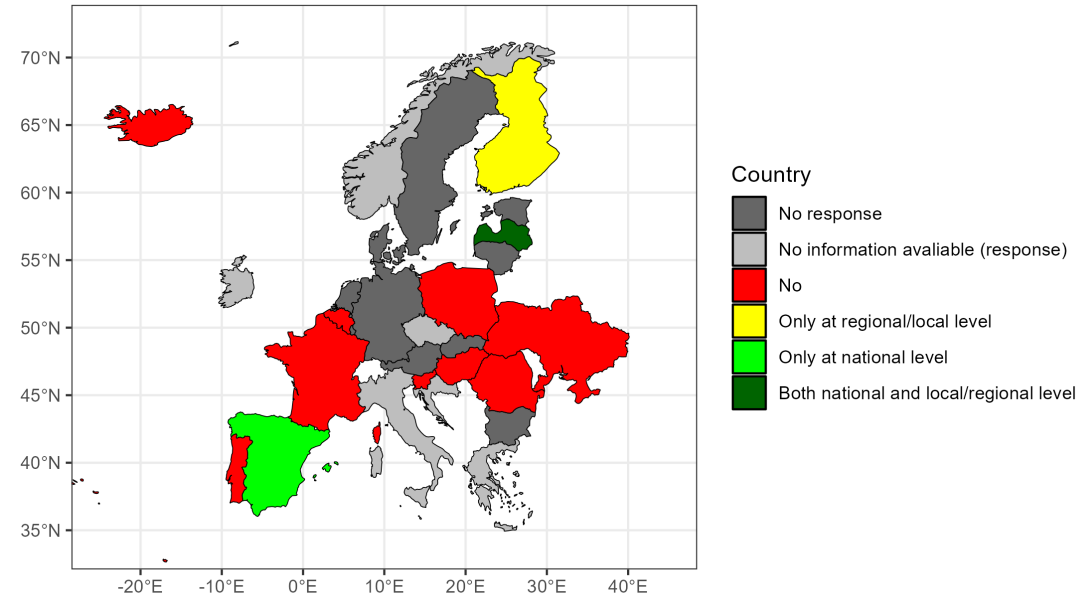
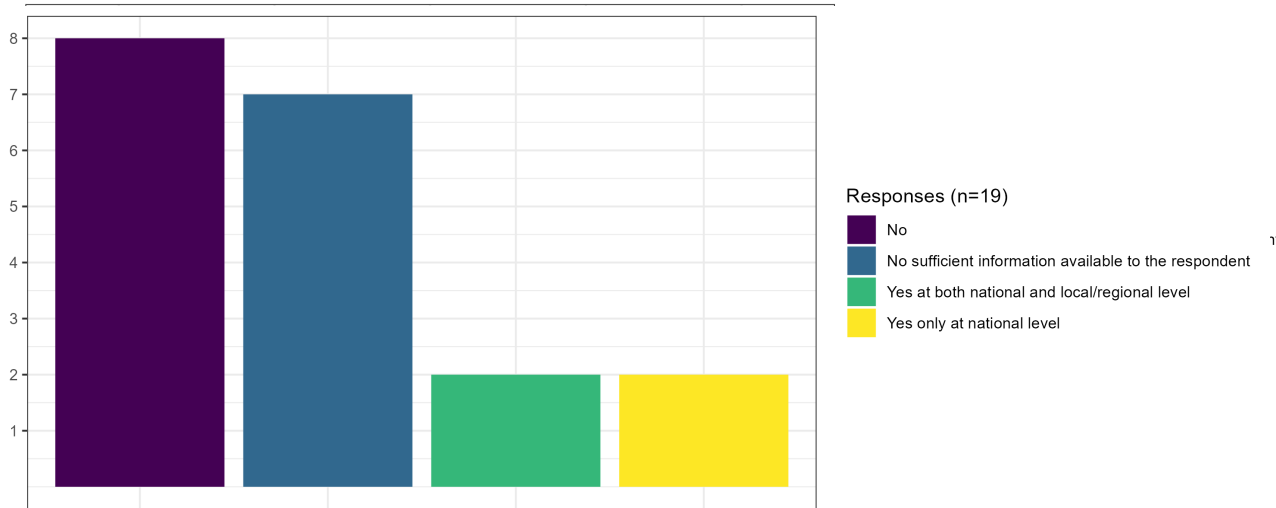
Are there guidelines for the systematic recording of patient-reported experience measures (PREMS)?



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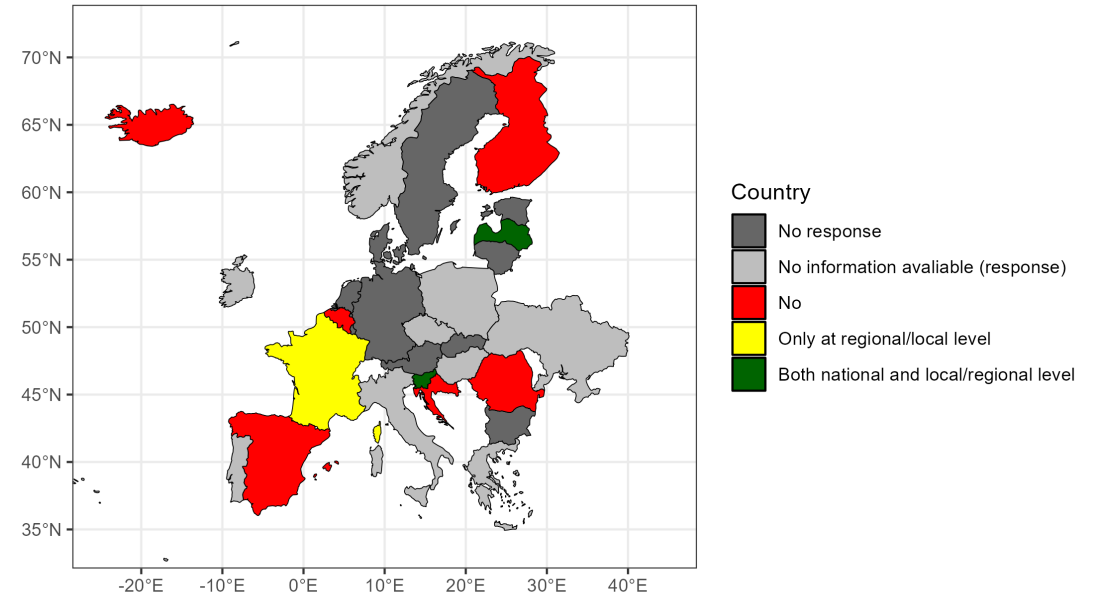
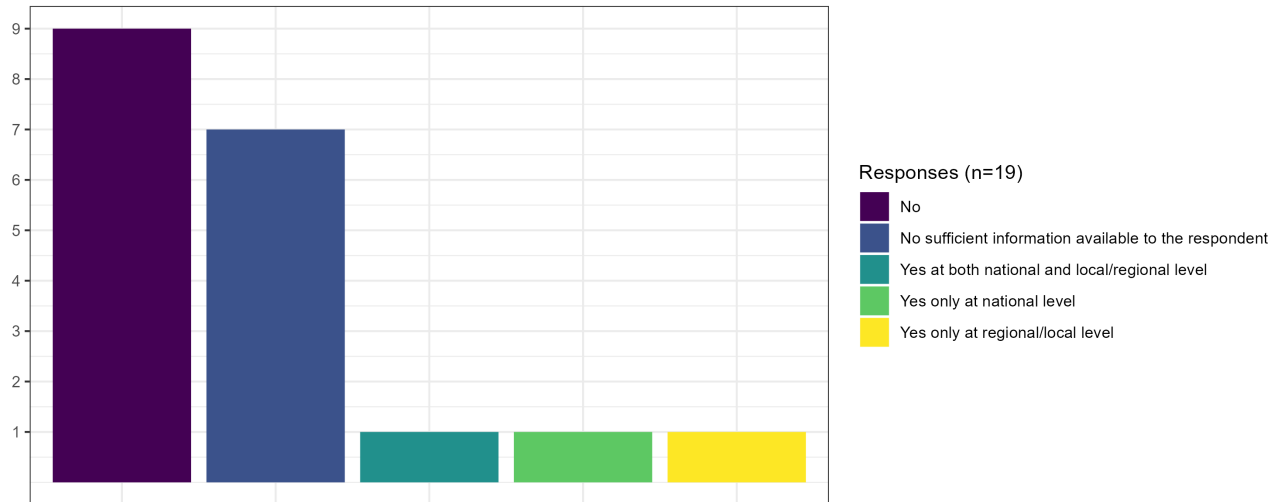
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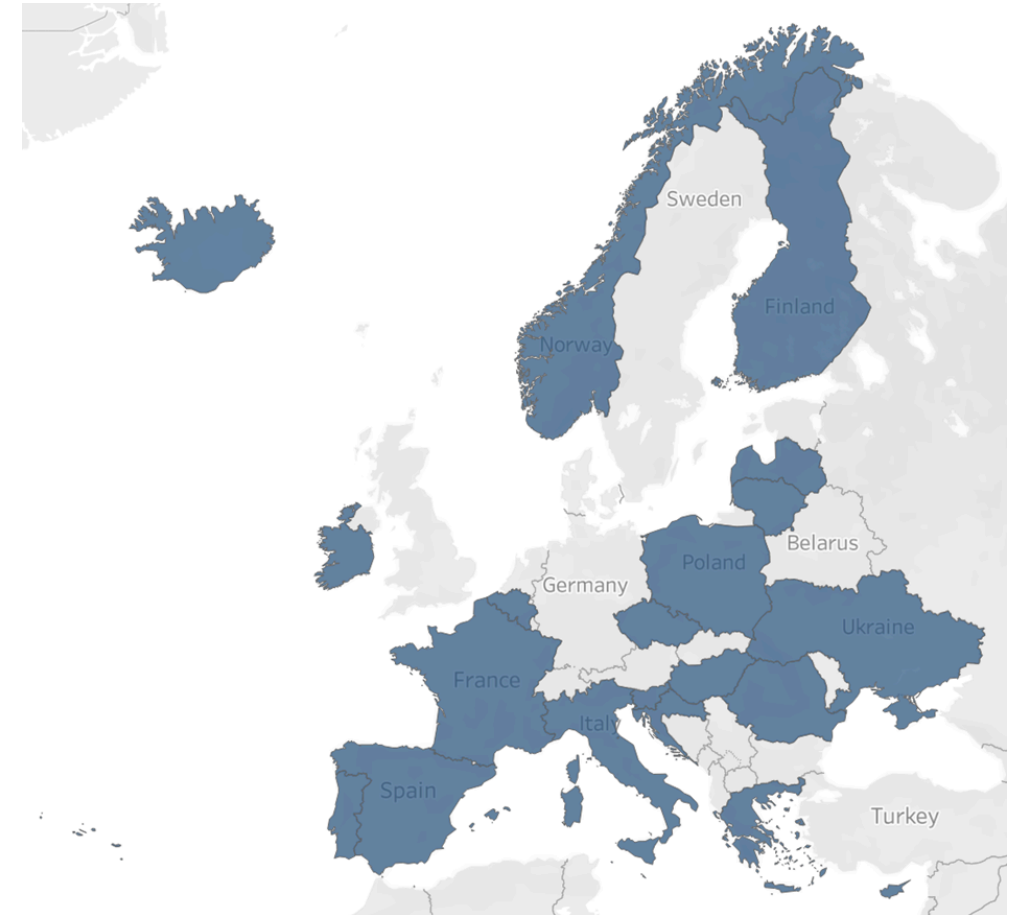
Are there recommendations on the use and implementation of common data models (e.g. OMOP, i2b2...) in all levels of the health system?



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Propuesta de sistematización datos en Salud CV de JACARDI

- Estructurar la información por niveles de cobertura
- Duration: 01 November 2023 – 31 October 2027
- Coordinator: Istituto Superiore di Sanità (Italy)
- Number of European Countries: 21
- Number of Partners: 76
- Pilots to be implemented: 142



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WP7 Pilots



Number of pilots: 43



Countries implementing: 8



Population reached: millions

10 pilots

To implement a national/local register in countries without existing DM registries to monitor epidemiological and clinical situations

To improve the quality and coverage of pre-existing registries and data sources on DM

11 pilots

To develop a web-based interactive tool to identify country or region-level gender inequalities in socio-economic factors and in DM indicators, and to assess the relationship between both gender gaps.

To develop a database designed to host the content, structure, and results of the critical information needed to know the epidemiological and clinical situation of DM

6 pilots

5 pilots

DM
24 pilots (56%)

CVD and DM
8 pilots (19%)

CVD
11 pilots (26%)

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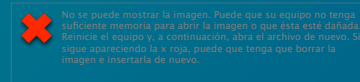
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Centro Nacional de Investigaciones Cardiovasculares (CNIC)



Profesor Asociado
Universidad Complutense de Madrid



Servicio de Cardiología y Area de Investigación Cardiovascular. Instituto de investigación i+12
Hospital Universitario 12 de Octubre, Madrid



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